

Screening Choices: A resource for health professionals offering antenatal and newborn care

Unit Understanding and communicating risk

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On behalf of the UK National Screening
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ISBN 0 9543684 3 6

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About this programme in the Toolbox.

Understanding and communicating risk

Creating a workbook



Recording your learning as you work through this unit will enable you to use it as evidence of your professional development. We have developed a workbook for this unit that repeats the activities to help you to structure your work. You can either print out the workbook if you prefer to work on paper, or save it onto your computer to work on screen.

When you have finished the unit you can keep the completed workbook in your professional portfolio with the certificate at the end of the unit, which you can sign to acknowledge your learning.

We recommend that you create your workbook before you begin studying the unit.

To create your workbook go to Toolbox, click on **Understanding and communicating risk** then click On-screen workbook or Printed workbook, depending on how you intend to use it.



Introduction

Welcome to *Understanding and communicating risk*, part of the UK National Screening Committee's training programme *Screening Choices: A resource for health professionals offering antenatal and newborn care*. The programme has been developed to meet the needs of all health professionals whose role impacts on antenatal and newborn screening. It aims to help you to develop the skills and knowledge you need to enable you to ensure women, their partners and families are offered informed choices in antenatal and newborn screening. For information on how to use these materials, please read the Introduction to the whole programme.

This unit aims to improve your understanding of risk as it applies to antenatal and newborn screening and to offer practical suggestions on communication of risk to pregnant women, new mothers and their families, and to enable you to ensure women can make informed choices about screening opportunities.

Learning outcomes

After studying this unit you will be able to:

- ☐ Acknowledge individual variation in perception of risk in both professionals and service users, give examples and understand the underlying factors
- ☐ Discuss the concept of framing and ways in which professional presentation of risk can influence women and their partners'/families' understanding
- ☐ Understand how epidemiology contributes to the understanding of risk in health and screening
- ☐ Explain absolute and relative risk and their relevance to the antenatal and newborn screening programmes
- ☐ Discuss different uses of the term 'risk' eg, chance, probability, uncertainty
- ☐ Understand the different approaches to communicating the same risk.

Before you begin to work through the unit, Activity 1 will enable you to evaluate your skills and knowledge in relation to communicating risk, and to recognise the areas you may need to focus on in particular. You may find that some areas are more relevant to you than others, and decide to study those at the advanced level after working through the unit at core level.

Activity 1



Use your workbook to do this activity

Self-assessment

This programme has been designed so you can build on your current skills, and to provide you with a framework to structure the new knowledge and skills you develop. Our intention is that you will work through the entire unit at core level, rather than use it to 'dip into'. You can then go back to work through some or all of it at advanced level if you feel it is appropriate for your practice. Studying the units in this way will enrich your existing knowledge, and help to apply it to your practice more effectively.

As a health professional busy 'doing the job' it can be difficult to stand back and identify the skills and knowledge you use in your everyday practice. To get the most out of studying this unit it is important to be aware of the extent of your existing knowledge.

The self-assessment below will help you to think about your knowledge and skills about risk. It is important to remember that this is simply an exercise to help you plan your learning. There are no 'right' or 'wrong' answers, and the responses you give are for your eyes only.

The self-assessment

Look at the six statements below and in your workbook rank how much you know about each, and how competent you feel about completing the task(s) involved in them. Use a scale of 1–5 (1 being NOT very competent and 5 being VERY competent).

1. I can acknowledge individual variation in perception of risk in both professionals and service users, give examples and understand the underlying factors.
2. I can discuss the concept of framing and ways in which professional presentation of risk can influence women and their partners'/families' understanding.
3. I understand how epidemiology contributes to the understanding of risk in health and screening.
4. I can explain absolute and relative risk and their relevance to the antenatal and newborn screening programmes.
5. I can discuss different uses of the term 'risk' eg, chance, probability, uncertainty.
6. I understand the different approaches to communicating the same risk.

Identifying your skills and knowledge

Use the scores you gave yourself for each statement to identify the areas of your practice you feel least competent about and where you are very confident. You might like to make some brief notes about what you would like to learn from studying the unit and how it could enhance the care you provide.

We will begin by looking at differences in the way people perceive risk, and how that might affect the decisions they make about antenatal and newborn screening.

Perceptions of risk

Antenatal and newborn screening programmes aim to benefit women and their families by giving them information about their own health, or that of their fetus or baby, that can enable them to make informed choices about treatment or other options. However, a range of risks is associated with screening and/or diagnostic tests and the implications of their results.

All the women, partners and families you work with will react differently to these risks depending on their perception of them. This will affect the way they try to come to decisions and what those decisions are. People's perceptions can be influenced by their capacity to understand the information, and other factors that are individual to them and their own circumstances, as the quotes below illustrate.

'I couldn't understand why Parissa and Jamshid were so worried when I told her the risk of their baby being affected by Down's syndrome had been calculated at one in 2,463 – most parents are relieved when they hear those sort of odds. However, when I explored it a little with them it turned out that Parissa's sister had been given a risk of one in over 4,000. Because the numbers were so different Parissa and Jamshid interpreted theirs as meaning high risk.' Midwife

'I associate numbers with personal experiences. When I [heard] one in 100 I immediately thought of my twins. It's a nice risk that I had twins.' (from Walter and Britten, 2002)

'But don't you think as you get older you become more aware of risk? Your perception of risk becomes more acute.' (from Walter and Britten, 2002)

Two women with exactly the same results, explained in exactly the same way, will not necessarily perceive their risk in the same way (Marteau, 1999; Walter and Britten, 2002). For example, a woman with a 25% risk of having a baby with a sickle cell disorder may not see this in the same way if a member of her family is mildly affected by the condition in question as another woman who has a severely affected relative. Equally, a woman who has decided that she would prefer to end a pregnancy if her baby was found to have Down's syndrome may see a one in 35 risk very differently to one who has decided to continue with her pregnancy even if it is affected.

The way people perceive risks and make decisions is also affected by the fact that the demands of daily life mean they often have limited time to make decisions of all kinds. In order to cope with this, they use a number of 'decision rules', known as heuristics, which help to provide quick answers. Three common heuristics are:

- **Availability** – people judge things to be more likely to happen if they find them easy to imagine or think of an example from their own experience. For example, someone who works with children with a particular condition may perceive their own baby's risk to be high, regardless of information such as numbers and percentages they may be given.
- **Representativeness** – people judge the probability of an event by finding a 'comparable known' event and assuming the probabilities will be similar. For example, a woman who has had a pregnancy in which a serious fetal anomaly was detected may assume her next will have the same problem, regardless of whether or not her pregnancy is considered to be at higher risk.
- **Anchoring and adjustment** – people use an initial piece of information as an 'anchor' and use other information to adjust this. For example, a woman who is told that she has a one in 35 chance of giving birth to a baby with Down's syndrome may see this as an acceptable risk until she is told that this means she is classified as being in the higher risk category.

These individual variations in the way women and partners perceive risks related to antenatal and newborn screening highlight the importance of ensuring discussions about risk are a two-way exchange of information and ideas. Simply providing information on risk without discussing their specific circumstances and perceptions will not help women and their partners to make informed choices.

Fright factors

Bennett (1997) says that certain risks trigger more alarm, anxiety or outrage than others, and that this depends on people perceiving them to be associated with a number of 'fright factors'. As you will see from the list below, most of these could be linked in some way with antenatal and newborn screening. Risks are generally more worrying – and less acceptable – if perceived:

- To be involuntary (eg, exposure to pollution) rather than voluntary (eg, parachuting)
- As inequitably distributed (some benefit while others suffer the consequences)
- As inescapable by taking personal precautions
- To arise from an unfamiliar or novel source
- To result from man-made, rather than natural sources
- To cause hidden and irreversible damage
- To pose particular danger to small children or pregnant women, or to future generations
- To threaten a form of death, illness or injury arousing particular dread
- To damage identifiable rather than anonymous victims
- To be poorly understood by science
- As subject to contradictory statements from responsible sources (or worse, from the same source).

Activity 2 aims to help you to understand what sort of factors might affect the way that women and their partners perceive risk and what these effects might be.

Activity 2

Perceptions of risk

Core

Think about the way in which women and their partners may perceive risk related to antenatal and newborn screening. In your workbook list the factors related to themselves and their own circumstances that might affect their perception of risk.

Advanced

Looking at the list of factors you generated in the core activity, think of an example of how each might affect the perceptions of women and their partners. You may want to use examples from your own practice.



Use your workbook
to do this activity

Feedback

Core

A wide range of factors may influence the way women and their partners perceive risk. However, your list may have included some of the following:

- Previous personal experience
- Their own physical and/or mental health
- Experience of illness among family members
- Obstetric history
- Cultural or religious values
- Personal attitudes to and understanding of risk, fate and inheritance
- Mood
- Age
- Controllability of risk and coping with uncertainty
- Previous health service experience.

Advanced

While the range of factors that may affect individual perception of risk is huge, the actual effect of the factors is unique to each individual. Your interpretation of these effects will depend on your own perceptions, or on your professional experience. However, we have given an example for each factor in our list from the core activity.

- Previous personal experience – having placed a bet with similar odds to a risk estimated by screening tests, and whether the bet was won or lost, could affect whether the odds are seen as acceptable.
- Their own physical and/or mental health – a woman with mental health problems may find the prospect of a child with special needs overwhelming and the risks of diagnostic tests acceptable even if they are higher than her risk of an affected pregnancy.
- Experience of illness among family members – a family member with a disability who lives a fulfilling life may reduce perceptions of the seriousness of that disability.
- Obstetric history – a woman who has had difficulty conceiving may see the risks of diagnostic tests as unacceptable.
- Cultural or religious values – a belief that events are the result of God's will might make people more accepting of the risk that a pregnancy may result in a disabled child.
- Personal attitudes to and understanding of risk, fate and inheritance – a feeling of being generally 'lucky' may make people see odds of 1:20 as a relatively low risk.
- Mood – relief at having given birth after a difficult pregnancy may make a woman more fearful for her baby's health.
- Age – having a first baby at an age when further pregnancies are unlikely may make a woman more accepting of the risks of having a disabled child.
- Controllability of risk and coping with uncertainty – difficulty coping with uncertainty can make a woman more likely to opt for a diagnostic test, even if she would continue with an affected pregnancy.
- Previous health service experience – a misdiagnosis that had negative consequences may make people less trusting of screening and diagnostic test results.

Finding out how women and their partners feel and assessing their existing knowledge will help you to identify what information and support they need to make informed choices in relation to antenatal and newborn screening.

*The unit **Informed choice for everyone: valuing diversity** will help you to understand how different factors may affect women, their partners and families.*

Presentation of risks

While factors related to their own experiences and circumstances can influence the way women and their partners perceive risk related to antenatal and newborn screening and the decisions they make as a result, another potentially major influence is the way health professionals present information about risk (Marteau, 1999). This is known as ‘framing risk’.

For example, being told ‘You have a one in 20 risk of having an affected baby’ may suggest a greater risk than ‘You have a 19 in 20 chance of having an unaffected baby’. It is important to understand that expressions of risk often carry a positive or negative message, and the potential for this to influence decisions about screening, as the quote below illustrates.

‘It wasn’t until I discussed it with a friend that he said to me, “Well actually that still means that you’ve got a 20 out of 21 chance of everything being fine”. But it’s just human nature to focus on that negative, rather than to focus on the positive, I think. And that’s obviously what we did until we had more information.’ Mother

You can also minimise the possibility that your framing of risk affects women and their partners’ decision-making by presenting information in a number of ways. So, rather than simply saying ‘You have a one in four risk of ...’, you could continue ‘or put another way, a 25% risk’ you can also add ‘but that also means you have a three in four or 75% chance of ...’.

Selective information-giving can also affect women and their partners’ ability to make informed choices about screening. You should therefore ensure you do not leave out information that may be important in their decision-making, such as details about conditions for which screening is being offered, or risks associated with diagnostic tests. In order to avoid framing risks in a way that may influence women and their partners’ decisions, it is important to be aware of your own views on the issues you are discussing. For example:

- Do you think women who are carrying babies affected by Down’s syndrome or sickle cell disorders should continue with their pregnancy?
- Do you feel women should only have diagnostic tests if they intend to terminate their pregnancy if it is affected?
- Do you feel that testing pregnant women for HIV is unnecessary if they are not in a higher-risk group?
- Do you feel that parents who decline newborn screening tests are irresponsible?

You may have strong beliefs about these and other issues related to antenatal and newborn screening. However, your personal values and beliefs should not influence your professional practice when presenting information on screening options or results, or what information you choose to give.

It can be difficult to avoid showing your own views – particularly in your non-verbal communication. You may also subconsciously give clues about your own attitudes and feelings through the language you choose. The quote below demonstrates how health professionals can inadvertently communicate their own views when discussing screening results.

‘When the results of my Down’s test came back, I was told I had a one in six chance of having an affected baby. I thought that was fine as there was a five in six chance of having an unaffected baby, but the midwife who told me obviously thought it was terrible news – it was written all over her face and she kept touching my arm like I needed comforting.’ Pregnant woman

*The unit **Getting the best from the consultation** discusses verbal and non-verbal communication and will help you to avoid letting your own attitudes influence the way you discuss screening.*

Activity 3 asks you to consider your own attitudes to risk in relation to antenatal and newborn screening and care, and your reactions to the attitudes of the women and families you work with.

Activity 3

Your attitudes to risk

Core

Look at the statements below:

1. 'I don't want any screening while I'm pregnant. My sister and friend had everything they were offered, and it just made them worry. Their babies were fine but the tests spoiled their pregnancies.'
2. 'They only offer CVS when there's a one in 250 or less chance of the baby having Down's syndrome. They told me there's a one in 850 risk of my baby having being affected – that's still a risk, and I want to have a CVS so I know for sure.'
3. 'I've cut down on my smoking, but I'm not giving up completely. I don't see how five or six a day can do any harm.'
4. 'If he has cystic fibrosis we'd rather not know until he gets ill. We'd only worry about it all the time.'
5. 'My mother-in-law said I shouldn't have a test for Down's syndrome. She said we should see our baby as a gift from God.'
6. 'I don't want them poking and prodding my baby. We just want to get her home – I'm her mother and I know she's fine.'
7. 'My friend told me there are lots of conditions they can test for while you're pregnant, but they only offer a few. I think that's terrible – if a test is available, everyone should have the chance to have it.'

Write down in your workbook how the statements make you feel:

- Do you strongly agree or disagree with any of them? Why?
- Would it affect your opinion of them if a woman and or partner said one of the statements to you?

Advanced

For each statement, discuss what your role would be if a woman and/or partner you were working with said it to you. What information, if any, would you need to give?



Use your workbook to do this activity

Feedback

Core

Some of the statements may have provoked strong feelings in you. You may have disagreed or felt impatient with the person saying them or have felt strong sympathy with their view. These feelings will have been affected by your own attitude to risk in general and in these specific circumstances, and by your professional knowledge and experience. Awareness of your own attitudes can help you to avoid allowing them to influence the way you discuss aspects of risk with women, partners and families. You can still use your professional knowledge and experience to discuss the issues and give them the appropriate information to ensure they are able to make informed choices.

Advanced

Some of these statements may suggest the women and partners have a different attitude to or understanding of the risks being discussed to your own. Your role in all these situations is to ensure that they fully understand the implications of any choices they are making, or the reasons why particular screening services are, or are not, offered.

Here we suggest ways that you could help women making these statements to make an informed choice.

1. *'I don't want any screening while I'm pregnant. My sister and friend had everything they were offered, and it just made them worry. Their babies were fine but the tests spoiled their pregnancies.'*

You would need to ensure this woman has all the information she needs about the purposes of screening programmes, to ensure she understands the possible implications if her baby is affected by any of the conditions tested for in the antenatal period. This could include information on incidence of particular conditions screened for, risk factors for them, what the tests involve and the effects of the conditions. You may provide written information for her to take away so that she can consider her decision further if she wishes.

2. *'They only offer CVS when there's a one in 250 or less chance of the baby having Down's syndrome. They told me there's a one in 850 risk of my baby having being affected – that's still a risk, and I want to have a CVS so I know for sure.'*

This woman may not understand the risk of miscarriage associated with CVS, and how this compares in numerical terms with the risk of her baby being affected with Down's syndrome. However, she may feel so strongly that she could not cope with a baby with Down's syndrome that she prefers to take the risk of having a CVS to give her a definitive answer. Your role would be to find the reasoning behind her statement. You would also have to ensure she understands how the risks of CVS and her baby being affected with Down's syndrome compare, and that she has a clear understanding of Down's syndrome. This will ensure her choice is fully informed. She may also find it helpful to contact an organisation like Antenatal Results and Choices (<http://www.arc-uk.org>) or the Down's Syndrome Association (<http://www.downs-syndrome.org.uk>). If your service has a cut-off point beyond which it does not offer free diagnostic tests, you may have to explain how she could explore the possibility of obtaining one privately if she wishes to do so.

3. *'I've cut down on my smoking, but I'm not giving up completely. I don't see how five or six a day can do any harm.'*

This woman may not fully understand the risks to the fetus of smoking during pregnancy, and the possible long-term health effects to her child when it is born.

NHS Pregnancy Smoking Helpline: 0800 169 9 169

The NHS Asian Tobacco Helpline offers confidential smoking cessation advice in five South Asian languages:

Urdu:	0800 169 0 881
Punjabi:	0800 169 0 882
Hindi:	0800 169 0 883
Gujarati:	0800 169 0 884
Bengali:	0800 169 0 885

However, she may understand these risks and have tried but failed to stop smoking, or believe the potential effects on the fetus caused by the stress of not smoking would be as great. You would need to explore her understanding of the effects of smoking, and offer smoking cessation literature or sources of help such as the NHS Stop Smoking Services (see box) or local smoking cessation clinics. Involving her partner or other family members in helping her to stop smoking or further cut down her cigarette consumption may also be helpful, but ultimately it is her decision whether or not she stops smoking.

4. *'If he has cystic fibrosis we'd rather not know until he gets ill. We'd only worry about it all the time.'*

The benefits of screening for cystic fibrosis (CF) are less clear-cut than other conditions in the newborn blood spot screening programme – particularly PKU and congenital hypothyroidism (CHT), for which early treatment is important to prevent damage to babies' development. However, your role would be to explain the potential benefits of early treatment and management of the condition, so that she can balance these against

the possible anxiety that knowing her baby had CF would cause. You would also need to explore her understanding of CF – for example whether there was a family history of the condition (if this has not already been established during antenatal care), or whether she has known someone affected by it, and whether she knows about treatment and management techniques.

5. *'My mother-in-law said I shouldn't have a diagnostic test for Down's syndrome. She said we should see our baby as a gift from God and we shouldn't do something that carries a risk of miscarriage.'*

In some families, other members as well as the prospective parents are closely involved in decisions about issues such as antenatal screening and diagnostic tests. You would need to explore whether this is acceptable to the woman and her partner, or whether they feel under pressure to make a choice that is not right for them. However, even if this is the case, they may feel the implications of disregarding the views of a senior family member are too great. There may also be religious reasons for them declining the test – knowledge of the teachings of religions prevalent in your local area may help you to know if this is the case.

If she is closely involved in decisions relating to the pregnancy, it may be helpful to involve the woman's mother-in-law and ensure she fully understands the issues related to screening for Down's syndrome.

6. *'I don't want them poking and prodding my baby. We just want to get her home – I'm her mother and I know she's fine.'*

Your role with these parents would be to ensure they understand all the conditions tested for in newborns, and the benefits of early identification. You should also ensure they understand what the tests involve, and the implications for their baby if conditions go undetected. If they still decline the tests it may be helpful to give them literature to take away, and to ensure that they know they can still have their baby tested if they change their minds in the future.

7. *'My friend told me there are lots of conditions they can test for while you're pregnant, but they only offer a few. I think that's terrible – if a test is available, everyone should have the chance to have it.'*

This woman may not understand the implications for the health service – and for women and families – of screening all pregnant women for all conditions for which tests are available. You would need to explain why screening programmes are set up for particular conditions. You would also need to explore why she has these concerns and whether they relate to any particular conditions. You may be able to reduce her anxiety, for example if she is worried about a genetic condition for which she has no family history.

*There is more on screening programmes in the unit **Screening in antenatal and newborn care** and its accompanying Factsheet, and more on genetic inheritance in the unit **Understanding genetics**.*

The next section looks at how risk impacts on screening programmes.

Risk in antenatal and newborn screening

The word 'risk' is used in many different contexts and, as a professional, it is important for you to understand these differences and use the terms precisely. When 'risk' comes into your consultations you must also realise that the women and families you work with will have their own understanding of the word and will use this and many other factors in their decision-making.

People use the word risk in different ways. They talk about risks in everyday life: crossing the road, travelling in an aircraft, being in town late at night, or smoking. They may also discuss the risks of buying and selling shares on the stock market. In these examples, they may be referring to the **likelihood** that something harmful will happen, or to their perception of the **potential seriousness** of that harm (Marteau, 1999). You probably use these concepts of risk in your consultations with patients. For example, you might talk about amniocentesis or CVS and the chance that the procedure could result in a miscarriage, or the potential effects of Down's syndrome on a child's health and development.

Communicating risk involves a combination of skills. You will need to be able to help women and their partners to understand relevant facts and figures and be aware of how other factors such as past experiences may influence their decisions.

As it is impossible to know whether a person will get a disease or whether a baby will have a disability at birth (unless accurate and reliable diagnostic test results are already available), health professionals can only try to make predictions. Most decisions in screening involve trying to balance the likelihood of the disease or disorder against any risks associated with the tests themselves – the **potential benefit** of screening against the **potential harm** of the tests. To help with this prediction and decision-making we rely on an analysis of the information derived from the past – from populations of similar people and what happened to them.

Epidemiology

Information on the risks and benefits of screening is derived from **epidemiological** studies. For example, we know from national data that the incidence of PKU in babies born in the UK is 11 in every 100,000 (Smith et al, 1991). There are around 600,000 babies born in the UK each year, so this means on average 66 are born with PKU. Since we don't know who these 66 will be, for any particular baby we can only say that the chance is about one in 10,000 or about 0.01% in the general population.

Researchers over the years have tried to make epidemiological information more useful by asking the question: *What makes people more or less likely than average to get the disease in question?* This can serve two main functions:

- From a research point of view epidemiology helps them to understand the causes of disease and how they could be prevented.

A classic example of how epidemiology increases understanding of the cause of disease is that of smoking. In the 1950s Sir Richard Doll first reported that people with lung cancer were much more likely to smoke than people without the disease. Smoking was identified as a **risk factor** for lung cancer. It was then possible to look at harmful constituents in the smoke ('carcinogens') as potential causes of lung cancer. It also gives the impetus for measures to be put in place to reduce smoking in the population such as a ban on tobacco advertising or the introduction of smoking cessation services.

- In a practical way epidemiology helps services to target particular groups or individuals for prevention measures or treatment.

Sickle cell disorders are more common in certain ethnic groups, so while all pregnant women are offered a screening test in high-prevalence areas, in areas of low prevalence screening involves finding out whether the woman is from one of the higher-risk groups.

Being from a particular ethnic group is a **risk factor** for sickle cell disorder.

*There is more on how screening programmes are set up to balance benefit and harm in the unit **Screening in antenatal and newborn care**. More information on sickle cell screening is available from the sickle cell and thalassaemia screening programme (<http://www-phm.umds.ac.uk/haemscreening>)*

Activity 4 at core level asks you to match risk factors to a number of diseases or conditions, while in the advanced activity you can evaluate your own practice in communicating risk and risk factors.

Activity 4

Risk factors

Core

You probably know about many risk factors for disease. Look at these two columns and see if you can match the disease or condition with its important risk factors:



Use your workbook to do this activity

Disease or condition	Risk factor
Having a baby with Down's syndrome	Having a diet high in saturated fats
Having a small baby	Having close relatives with colon cancer
Cervical cancer	Having a family member with a genetic condition
Being born with an inherited problem	High blood pressure
Having a motor vehicle accident	Smoking in pregnancy
Developing heart disease	Having human papilloma virus infection
Having a stroke	Being male
Colon cancer	Maternal age over 40 years

Advanced

Think about a recent consultation in which you discussed risk factors related to a condition for which antenatal or newborn screening was being offered. Evaluate how well you were able to explain the risk factors. Think about:

- Whether you understood the relevance of known risk factors – how they influence the likelihood of a fetus or baby being affected
- Whether you were able to ascertain the woman and/or her partner's level of understanding and needs for information and support
- Whether you could answer the woman and/or her partner's questions in a way that was meaningful to them
- Whether they understood how the risk factors applied to them and their fetus or baby at the end of the consultation.

After evaluating your discussion, think about how you could improve future consultations on this topic. Rehearse the improvements by thinking through a consultation.

Feedback

Core

In matching the risk factors to the diseases, the correct answers were:

Disease or condition	Risk factor
Having a baby with Down's syndrome	Maternal age over 40 years
Having a small baby	Smoking in pregnancy
Cervical cancer	Having human papilloma virus infection
Being born with an inherited condition	Having a family member with a genetic condition
Having a motor vehicle accident	Being male
Developing heart disease	Having a diet high in saturated fats
Having a stroke	High blood pressure
Colon cancer	Having close relatives with colon cancer

It is important to know about major risk factors related to the conditions screened for in antenatal and newborn care (where they are known), and to be able to explain these to the women and families you work with as the quote about sickle cell disorder (below right) demonstrates. You may also find that you are asked about the influence of particular risk factors, as in the quote on Down's syndrome (below left). While you may not know these, you should know where you can find more information, or to whom you can refer them for more expert help. You should also understand how some risk factors may have a higher incidence in particular groups in society, and ensure you have the resources and support necessary to explain risk factors to different groups, such as those whose first language is not English.

Advanced

When thinking about how you could improve future discussions on risk factors, you may have decided you need to develop your practice in some way, for example:

- To develop a deeper understanding of the condition in question and the influence of known risk factors by working through learning materials from the screening programmes
- To develop your communication skills by working through the unit *Getting the best from the consultation*
- To find different ways of explaining the relevance of the risk factors, perhaps using visual aids or family trees
- To develop new resources and information that will make the discussion of risk factors meaningful to women of different cultures or those whose first language is not English, or to meet the needs of women with different levels of education.

Spend some time developing your knowledge, skills or resources as necessary.

'I was explaining how a mother's age can affect the risk of her baby being born with Down's, and how, at 24 Mrs Shah was likely to have a relatively low risk. Then she told me that her sister had Down's, and asked me whether that meant her baby was likely to have it. I knew family history was relevant, but I wasn't sure exactly how.' Midwife

'When we asked my GP about the chances of our baby having sickle cell disorder he started talking about how if one parent was a carrier and one had the disorder the risk was this for the baby having it and that for being a carrier and so on. I couldn't really follow it properly, and I don't think my husband could either. Then he showed me a diagram that had all the different possibilities, and talked through it with us. All of a sudden it made sense – we took the diagram away so we could remember how it works.' Pregnant woman

The next section looks at different types of risk and their relevance in antenatal and newborn screening.

Absolute and relative risk

Epidemiologists talk about absolute risk and relative risk. These terms are useful in different situations, but if used inappropriately could cause misunderstanding and lead health professionals and service users to make ill-informed decisions.

Absolute risk is the risk of developing a disease or condition over a particular time period. It answers the question *What is my percentage chance of getting the disease?*

The critical factor for interpreting absolute risk is the *time dimension*. A risk value is only meaningful if we know the time period over which it applies. For example, you might

read in a newspaper that women who are 60 years old have a 2% risk of dying from heart disease. Unless a time period is given this could mean anything from 2% of women die of heart disease as soon as they reach the age of 60 to 2% of women who reach the age of 60 will die of heart disease at some time from 60 onwards. To be meaningful, the statement would need to say that women who are 60 years old have a 2% chance of dying of heart disease within X years.

Relative risk is the incidence of a disease in an 'at-risk' group divided by the incidence of the disease in those not 'at risk'. (**At-risk** groups are those who possess risk factors associated with particular diseases, such as smoking, drug-taking, older age, particular ethnic group etc.) Relative risk answers the question *How many times more likely are those 'at risk' to get the disease than those not 'at risk'?* It is

useful when considering possible causes of the disease but is not usually useful in the context of discussions about the advantages and disadvantages of screening.

Be careful. It is easy to misunderstand different risks, or to use them in a misleading way. Look at the example in the box above. Activity 5 asks you to explore the concepts of absolute and relative risk and how these are communicated to women and their partners.

Reporting of risk – relative risk

Gigerenzer (2002) cites the example of an official statement concerning a research study on side-effects of the contraceptive pill (Jain et al, 1998). The statement reported that combined oral contraceptives containing desogestrel and gestodene **doubled** the risk of thromboembolism (ie, **relative risk** is 2). The concerns this caused among both women and doctors led many women to stop taking the Pill and resulted in an increased number of unwanted pregnancies and terminations of pregnancy. Although a doubling of the risk sounds frightening, in fact, the risk of thromboembolism had increased from only one in 14,000 to two in 14,000 (ie, one in 7,000).

Activity 5

Core



Use your workbook to do this activity

Communicating absolute and relative risk

Look at the statements below and decide whether they refer to absolute or relative risk:

1. Around 250 babies of the 600,000 babies born in the UK this year will have sickle cell disorders (UKNSPC, 2005).
2. Pregnant women aged 40 have a 15 times greater risk of having a baby with Down's syndrome than those aged 20 (National Down's Syndrome Screening Programme, 2004).
3. Children whose parents both carry the gene for cystic fibrosis are twice as likely to be unaffected carriers than they are to be affected with the condition (UKNSPC, 2005).
4. Women with HIV infection have a 25–45% risk of passing the virus to their children during pregnancy, birth or when breastfeeding if they do not receive preventive treatment (Avert, 2005).

Advanced

Consider the issues you need to be aware of when discussing with women and their partners absolute and relative risk in relation to antenatal and newborn screening. Think about this in the context of your own practice or discuss it in relation to the statements in the core activity.

Feedback**Core**

1. This refers to the **absolute risk** of sickle cell disorder for all babies born in the UK this year.
2. This refers to a **relative risk**. The risk of having a pregnancy affected by Down's syndrome is 1:1,500 in women aged 20, and 1:100 in women aged 40.
3. This refers to a **relative risk** – children born to parents who both carry the gene for CF have double the chance of being unaffected carriers as they do of having the condition.
4. This refers to an **absolute risk** of vertical transmission of HIV from mother to child if mother and baby do not receive prophylactic treatment and the mother breastfeeds.

Advanced

Absolute and relative risk can be extremely helpful to women and their partners when making choices related to screening. However, unless they are used in the proper context and explained correctly they do not give all the information necessary to ensure these choices are fully informed. As the quote below illustrates, discussion of risk can be extremely confusing for parents if they do not receive all the information they need.

'You're not really told how accurate is this test, because everything is all risks and statistics, and we all know about stories of, "They told me it was going to be like that, and it turned out exactly the opposite." ... And that is something I think they haven't really explained to people. So they tell you, "You have your anomaly scan. Come, have it and that's it – it's normal, or it's abnormal." But what does that really mean? Because the fact that they told me it's normal, doesn't mean that it is normal 100%. I could still have a baby with some problem. I know they are concepts that are a bit difficult to grasp, perhaps, because they imply statistical analysis and things like that, but it can always be made easier to understand for everybody.' Pregnant woman

The specific advantages and potential disadvantages of discussing absolute and relative risk will depend on your own role in antenatal and/or newborn screening. However, if you discussed the statements in the core activity you may have come up with some of the following:

1. Discussing the absolute risk of being affected by sickle cell disorder in terms of all babies born in the UK is probably not helpful. Because the condition primarily affects people from particular ethnic groups, discussing risk as it relates specifically to these groups will give more meaningful information (eg, in Britain SCD is most common in people of African and Caribbean descent – at least one in 10–40 are unaffected carriers and one in 60–200 have SCD) (Sickle Cell Society, 2004). However, as the number of mixed-race relationships increases it is becoming more difficult to use statistics relating to particular groups.

If other risk factors are known, such as whether or not one or both parents are affected or are unaffected carriers, risk related to inheritance patterns will give parents more meaningful information.

2. Maternal age is an important risk factor for Down's syndrome, and it can be useful to illustrate this. However, using the relative risk alone does not give useful information about an individual woman's risk, and may cause disproportionate anxiety. In addition, age is not the only risk factor – for example a previous history of Down's syndrome is also relevant. Screening can give additional information on an individual woman's risk where parents wish to decide whether or not to have invasive diagnostic screening.
3. While relative risk can be used to compare risk between groups, it does not give meaningful information on levels of risk. For parents who both carried the CF gene, relative risk would be less useful than information about inheritance patterns. This would demonstrate that their child would have a 25% risk of being affected by CF, a 50% risk of being an unaffected carrier, and a 25% risk of being completely unaffected. However, since screening for CF is not yet universally offered, many parents will be unaware whether or not they carry the CF gene.
4. Women with HIV infection have a 25–45% risk of passing the virus to their children during pregnancy, birth or when breastfeeding if they do not receive preventive treatment (Avert, 2005). This absolute risk would be useful in some situations, for example in discussing an offer of prophylactic treatment with a pregnant woman with HIV infection. However, it would also benefit her to know other information such as the fact that treatment for herself and her baby and avoiding breastfeeding can reduce this risk to as little as 2%.

Part of your professional expertise is in weighing up whether a woman has risk factors for particular problems and this may come into some of your discussions in her antenatal care and care of her newborn baby. Looking back at the examples in Activity 3, you will, for example, certainly want to find out whether she, her partner or other close family members smoke, and give advice to stop smoking in order to protect their baby's health. You might also enquire whether they have other risk factors such as drug-taking or a history of depression so that you can make sure that appropriate support is available. You will also be able to understand how you can discuss that risk in qualitative (risk factors) and quantitative epidemiological (incidence of disease, absolute risk, relative risk) terms.

Sometimes, although we can identify risk factors, we cannot use these to target our interventions. For example, although we know that some higher-risk groups such as intravenous drug users are at increased risk of HIV, we cannot just target these groups. This is because cases in other groups may be missed or all those in higher-risk groups may not be identified, while the consequences of a missed diagnosis can be extremely severe for both mother and baby. Thus, for HIV a whole-population approach is recommended, in which all pregnant women are offered HIV screening, and based on available evidence, midwives are urged to recommend HIV screening in each pregnancy.

Risk/chance as probability

We have seen that professionals engage in ordinary discussions about risk with their patients (the risk of miscarriage after amniocentesis or CVS), and also that 'risks' come into epidemiological terms with precise definitions – the absolute or relative risk of a particular disease, or condition. However, there is a third way in which we use 'risk', which is simply as another word for chance, probability or likelihood. Used in this way it is much the same as you might describe your chances of winning the lottery.

Using 'risk' in this way is very similar to the way in which mathematicians use the word 'probability'. A good example of this is the common maths problem: if I have 10 balls in a closed bag, all identical in size, nine red and one blue, what is the probability that when I take out one ball it will be blue? The answer is one in 10.

The word 'risk' is also used in this way in epidemiology. But, in dealing with women and families, it is not always as simple this. Most people can probably remember standing in a line of 10 and wondering if they will be picked for the sports team (although in this case being picked is unlikely to be random). However, they may have more difficulty in visualising bigger numbers such as 'one in 100' or 'one in 1,000' or they may simply have difficulty in understanding what 'one in 10' means. So we need other ways of explaining it to them. The next section aims help you to communicate with women and families about risk.

Terminology and communication methods

When discussing antenatal and newborn screening, you probably use a mixture of methods to help women and families understand their situation and make informed choices. These can include words, numbers, percentages, risk groupings and visual representations. Since different people understand and respond to different methods, Calman and Royston (1997) suggest that using a combination of several will improve understanding.

Activity 6 asks you to consider the use of a number of methods of conceptualising risk.

Activity 6

Core



Use your workbook to do this activity

Methods of communicating risk

This activity is based on a risk game derived from Kitzing (1990). It was developed for discussions about the menopause and HRT (Walter and Britten, 2002). Look at the random lists below of mortality rates per year in Britain, numbers/odds and community scales. In your workbook reorder the information to match mortality rates with numbers/odds and the community scale, then try to decide which could be described as: 'Moderately high', 'Moderate', 'Very low' and 'Minimal':

Mortality rates	Numbers/odds	Community scale
Deaths from murder	1:1,000	One person in a large town
Deaths from oral contraceptives	1:100	One person in a street
Deaths from any cause, age 40	1:1,000,000	One person in a village
Deaths from any cause	1:100,000	One person in a city

Advanced

Look at the incidence among babies born in the UK of the conditions tested for in the newborn blood spot screening programme (below). Try to come up with some different ways of conceptualising these numbers that you could use when discussing the tests with the parents and families you work with. Try to think of any information or statistics you could use to make them meaningful to different groups in your community.

Condition	Incidence
Phenylketonuria (PKU)	1:10,000
Congenital hypothyroidism (CHT)	1:4,000
Sickle cell disorder	1:2,500
Cystic fibrosis	1:2,500

Feedback

Core

In the risk game in Activity 6, the correct groupings were:

	Mortality rates	Numbers/odds	Community scale
Moderately high:	Deaths from any cause	1:100	One person in a street
Moderate:	Deaths from any cause, age 40	1:1,000	One person in a village
Very low:	Deaths from murder	1:100,000	One person in a large town
Minimal:	Deaths from oral contraceptives	1:1,000,000	One person in a city

You may have found it easier to relate to the description in the community scale, whereas others may find the numbers/odds easier to understand or vice versa.

Advanced

Many people find it difficult to identify with large numbers like those concerned with newborn blood spot screening, but they may find it easier if the numbers are related to something familiar and meaningful to them. Having a range of methods of conceptualising these numbers will help you to communicate them to different people. You could include local information that would be meaningful to people in your community, such as:

- The number of people regularly attending the local football team's matches
- The number of pupils at a nearby school
- The population of a village in the area
- The number of people living on a local estate
- The number of spaces in a supermarket car park
- The number of people employed in a local industry.

You may find it useful to come up with a range of methods to communicate other aspects of risk you discuss with women and their partners in relation to antenatal and newborn screening.

Words related to risk

As already discussed, because of the way they use the word 'risk', most people will perceive the word in a negative way. This can affect the way they interpret what you have told them. Other words, such as 'chance', 'possibility', 'probability', 'likelihood', 'uncertainty' and 'danger' may lead to different understandings – and hence feelings – about the same situation. Activity 7 will help you to reflect on the use of different words when discussing antenatal and newborn screening.

Activity 7

Interpretation of words

Core

Look at the list of sentences below:

- 'The test results suggest your **risk** of having an affected baby is ...'
- 'The test results suggest your **chance** of having an affected baby is ...'
- 'The test results suggest there is a [...] **probability** that your baby will be affected.'
- 'The test results suggest there is a [...] **likelihood** that your baby will be affected.'
- 'The test results suggest the **degree of uncertainty** about whether your baby will be affected is ...'
- 'The test results suggest the **danger** of your baby being affected is ...'



Use your workbook to do this activity

Did you feel that any of the words were inappropriate in the examples given? If so, why?

Which words do you use? Do you think you could choose more appropriate ones?

Advanced

In your workbook discuss the different connotations of the words used to communicate risk in the list above, and their possible effects on a woman's and/or her partner's perception of a situation. How might each best be used when discussing antenatal and newborn screening? Do you think any should not be used at all? If so, explain why.

Feedback

Core

In Activity 7 you may have felt that 'danger' was inappropriate because it sounds too negative, and that 'chance' sounds too positive when discussing the possibility that a baby may be affected. Did you feel that any of the words conveyed neither a positive nor a negative message?

Advanced

Activity 7 should have increased your awareness of how the words you use when discussing concepts of risk can influence women's interpretations. You may find it beneficial to discuss with colleagues the terminology used within your unit or service, to ensure everyone understands its potential impact, and agreement can be reached on which terms are preferable in different circumstances. This may avoid unnecessary distress or anxiety due to the casual use of terminology, or misunderstandings due to the inconsistent use of terminology.

Numbers, percentages and odds

When trying to communicate a degree of risk, it is likely that you use numbers, percentages and/or odds:

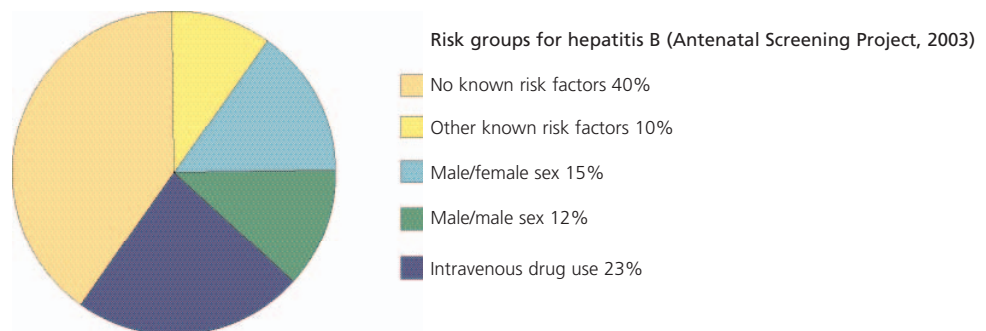
- 'There is a one in five chance'
- 'There is a 20% risk'
- 'The odds are five to one'.

Some people may find it easier to understand one of these than the others, and it is good practice to use more than one and to find out if those you are working with have a preference. For example, you might say 'The odds are five to one that the baby is affected – to put it another way there's a 20% risk that it is. Do you understand that, or would you like me to explain it in another way?' However, you should be consistent in your use of terminology. For example, you should not say 'You have a one in 240 risk of having a baby with Down's syndrome and a 1% risk of miscarriage if you have a diagnostic test.'

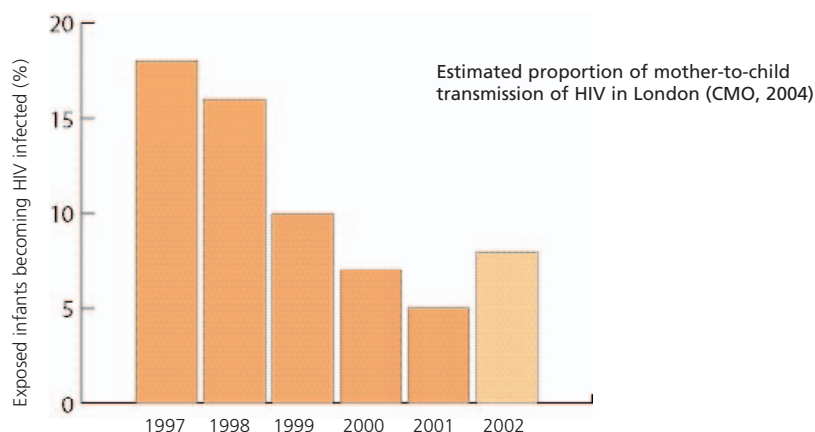
Visual representations

Some people find it easier to understand concepts of risk if visual aids are used to reinforce explanations. For example a 1% risk could be shown using 100 marbles in a bowl, with 99 of one colour and one of another, or by 99 circles of the same size and colour on a piece of paper and one triangle of a different colour. Other visual methods might include:

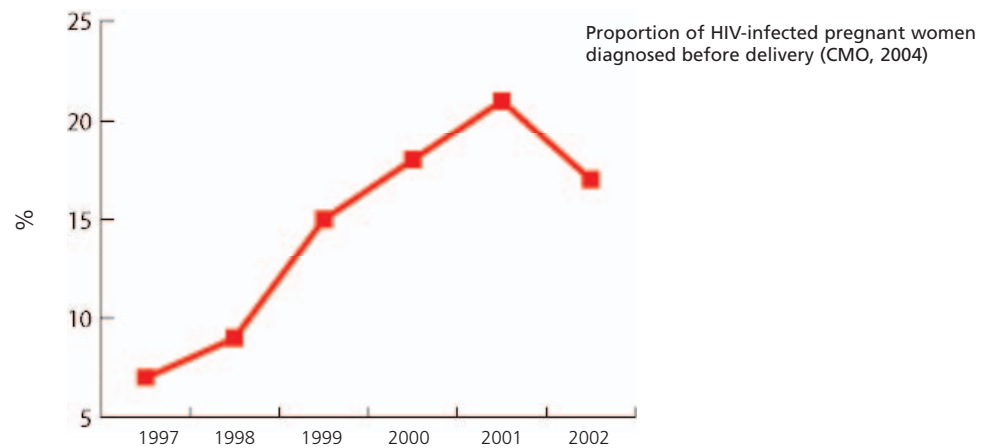
- **Pie charts** are useful in comparing parts to a whole.



- **Bar charts** are useful to communicate variables between groups or across time.



- **Line graphs** are useful to communicate trends or forecasts, and may include time as a variable.

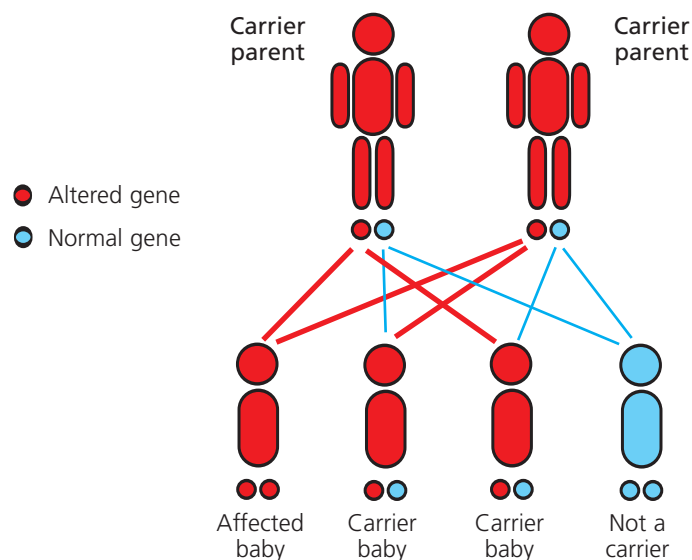


- **Tables** are useful to compare different groups, particularly when there are a lot of variables

Ultrasound finding	Odds of being affected by trisomy 13 or 18, given a positive result	Prevalence per 1000 births
Neural tube defects	1: 80	1.5
Holoprosencephaly	1: 0.03	0.1
Dandy Walker syndrome	1: 0.17	≤0.1
Hydrocephaly	1: 46	1.0
Agenesis of corpus callosum	1: 1.7	0.1
Diaphragmatic hernia	1: 9	0.5
Cleft lip with or without cleft palate	1:14	1.5
Exomphalos	1:7	0.5
Double outlet right ventricle	1:5	0.1
Hypoplastic left heart	1:40	0.5
Atrioventricular septal defect	1:43	0.5
Ventricular septal defect	1:26	3.5
Hydronephrosis etc	1:18	1.0
Limb reduction defects	1:17	0.5

Prevalence of fetal anomalies (Wald et al, 2000)

- **Family trees** are useful to communicate patterns of genetic inheritance



It is important to choose the visual method that best fits the information you are trying to convey, and to ensure that visual representations give information in a neutral manner. For example, avoid using smiling and sad faces, or black and white icons in favour of icons of different shapes or of colours without ethnic associations.

Risk groupings

The results of screening tests usually give a risk of a condition rather than a diagnosis. They are often put into risk groupings, such as higher or lower risk. These classifications can vary widely from one condition to another. For example, if a test for Down's syndrome shows a risk of one in 250 or fewer, it is judged to be in the higher-risk group (Down's Syndrome Screening Programme, 2004). A woman's increased risk of breast cancer due to family history however, is classified as low if it is around one in 10 because this is approximately the risk for the general population; breast cancer is a much more common condition than Down's syndrome. However, these different classifications of similar sized risks can cause confusion and you should be careful when using these words.

Activity 8, which is at core level only, aims to help you to understand why different methods of communicating risk work for different types of information.

Activity 8

Describing risk

Look at the list of risks (1–5) below and match them with the method of describing risk (a–e) you think would be most suitable:

1. Risk of inheriting cystic fibrosis when parents' carrier status is unknown
2. Effect of age on risk of having a pregnancy affected by Down's syndrome
3. Effect of taking folic acid on risk of pregnancy being affected by neural tube defect (NTD)
4. Diagnoses of syphilis in women in England and Wales 1999–2003
5. Risk of inheriting a haemoglobin disorder when one or more parents' carrier status is known.

- a. Pie chart
- b. Community scale
- c. Table
- d. Family tree
- e. Line graph



Use your workbook to do this activity

Feedback

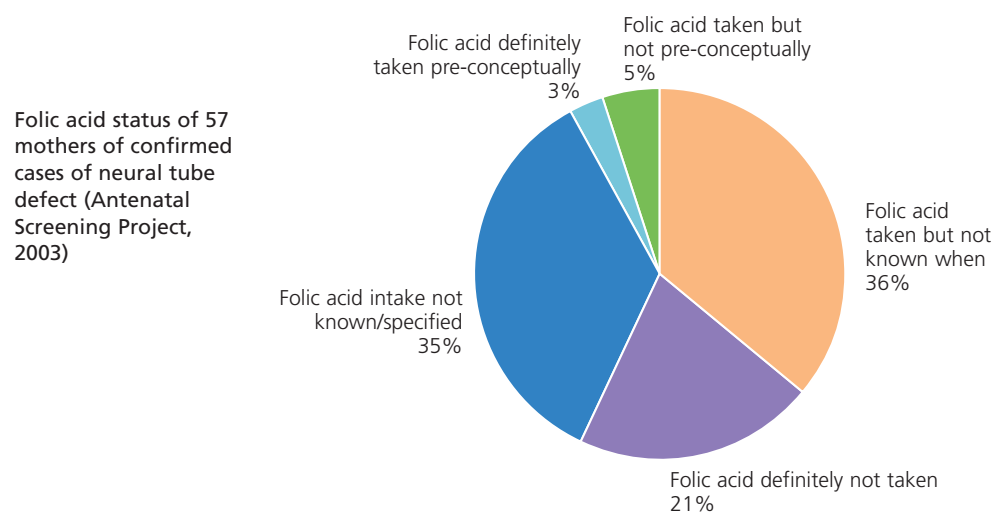
As we have already discussed, different people find different communication methods helpful in understanding concepts such as risk, so you may need to use more than one method when discussing issues of risk associated with antenatal and newborn screening. In the list of risks and communication methods, the following matches would work:

- 1 b** If parents' carrier status for CF is unknown the most useful way to explain the risk is to use the overall prevalence in the UK of one in 2,500 live births. To make such a large number meaningful a community scale would probably be the most effective – for example you might put the risk in the context of the population of a local village with a population of around 7,500, saying that on average three would be likely to be affected.

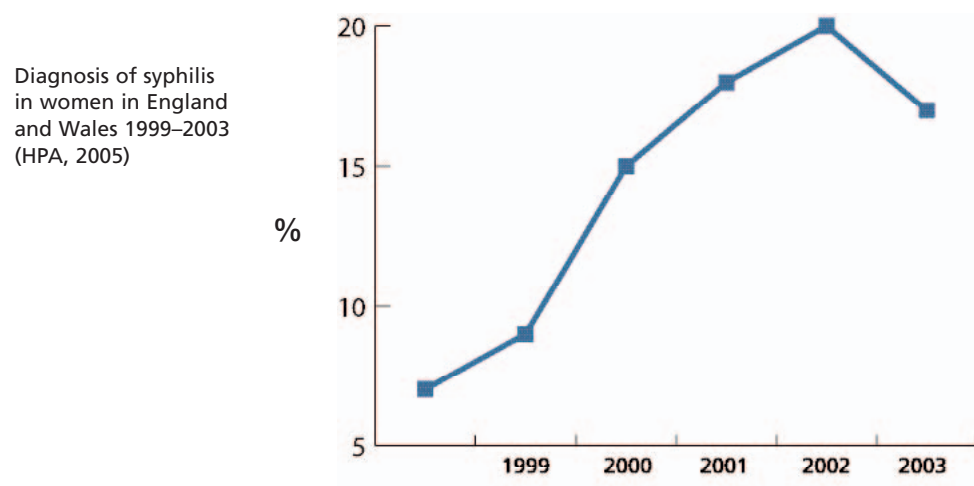
- 2 c** The age-related risk of Down's syndrome can be expressed as a ratio or a percentage, and differs greatly between women aged 20 and those aged 45 or over, so Table 2 (Down's Syndrome Screening Programme, 2004) would be useful to describe this:

Table 2. Levels of risk of having a Down's syndrome pregnancy in relation to a woman's age		
Woman's age	Risk as a ratio	Risk as a percentage
20	1:1,500	0.066
30	1:800	0.125
35	1:270	0.37
40	1:100	1.0
45 and over	1:50 and greater	2.0

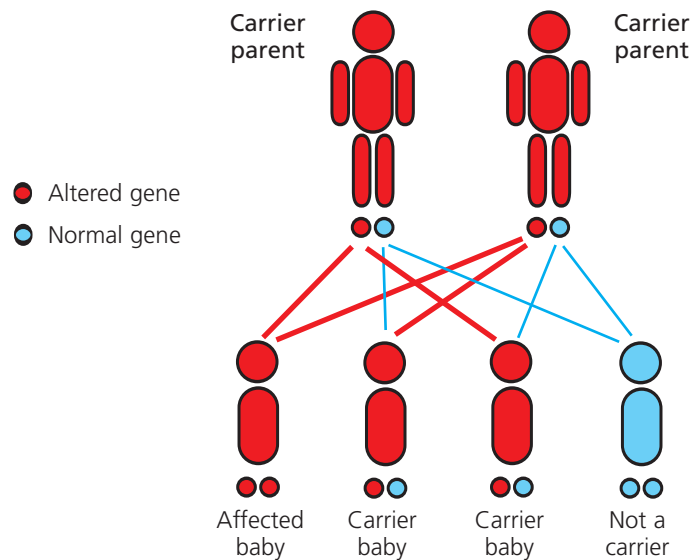
- 3 a** Ideally, when cases of neural tube defects are reported, information will include whether or not the mother took folic acid (FA) before and/or during pregnancy. However, this information may not be available in all cases – either because the woman is unsure or the information is not available. A pie chart can illustrate the proportion of each possible group, showing how many of the women definitely took folic acid:



- 4 e** Line graphs are useful for depicting infection rates over time, as they clearly depict trends as well as actual numbers of infections reported:



5 d Prevalence rates of haemoglobin disorders vary between different ethnic groups. However, as the numbers of mixed-race relationships increase, these prevalence rates are becoming less useful and meaningful. Also, if parents' carrier status is known, the risk of a pregnancy or newborn baby being affected can be calculated much more precisely than simply by describing prevalence in a particular group. Since the conditions are autosomal recessive, inheritance depends on the carrier status of both parents, so there are a number of possible permutations. Family trees can help to explain the risk of a pregnancy or baby being affected, unaffected or an unaffected carrier depending on the parents' status.



Conclusion

In summary, it is important to appreciate that communicating about risk is a two-way process (Edwards et al, 2002). It does not simply involve you giving information to women and their partners, but should be an exchange of information. This will help you to give information in the most meaningful way to ensure that they understand it. We hope that working through this unit has enabled you to improve your understanding of risk as it relates to antenatal and newborn screening.

Activity 9 is another self-assessment that should help you to check whether you have met your learning outcomes and identify any areas where you may need to increase your skills or knowledge. Other units in this programme, or materials from the other antenatal and newborn screening programmes, may help you with this.

Activity 9



Use your workbook
to do this activity

Self-assessment

Look at the self-assessment statement below and in your workbook rank how much you know about each, and how competent you feel about completing the task(s) involved in them. Use a scale of 1–5 (1 being NOT very competent and 5 being VERY competent). Compare your scores with the self-assessment you did before studying the unit.

1. I can acknowledge individual variation in perception of risk in both professionals and service users, give examples and understand the underlying factors.
2. I can discuss the concept of presentation of risk and the ways in which framing can influence women and their partners'/families' understanding.
3. I understand how epidemiology contributes to the understanding of risk in health and screening.
4. I can explain absolute and relative risk and their relevance to the antenatal and newborn screening programmes.
5. I can discuss different uses of the term 'risk' eg, chance, probability, uncertainty.
6. I understand the different approaches to communicating the same risk.

What now?

If you feel you still need to improve your skills and knowledge you may want to look at the additional resources listed in the Toolbox. Alternatively, you may need to study materials provided by the screening programmes, or other units within this programme.

Focus activity



Use your workbook
to do this activity

Explaining risk

This focus activity is designed to help you apply what you have learned by working through the unit to situations you might encounter in clinical practice.

Case example

Bridgeen gave birth to her daughter Bernadette yesterday and is preparing to leave hospital with her husband Liam. You come to check on her and Bernadette, and she asks: 'Are you going to do her blood spot now?' You explain that the community midwife will do this when Bernadette is about a week old.

Bridgeen and Liam look anxious and Liam says: 'Can't you do it now? If there's anything wrong we want to get things moving.'

When you explore the reasons for her anxiety Bridgeen tells you: 'My sister is training to be a midwife, and she's been telling us about all the screening tests we get. She told us that Irish people have double the risk of a condition called PKU and that for every day they aren't treated their IQ goes down. We don't want that to happen to Bernadette.'

You know that the incidence of phenylketonuria in the general population is around one in 10,000, and one in 5,000 in the Irish population, and that babies with the condition need to be put on a low phenylalanine diet by the time they are 21 days old to avoid neurological damage. How would you allay Bridgeen's and Liam's anxiety?

Think about:

- Fright factors and perceptions of risk
- Absolute and relative risk
- Methods of communicating risk

References

- Antenatal Screening Project (2003) Kohner, N. *Epidemiology Review*. Cardiff: Provincial.
- Avert (2005) HIV, *AIDS and Pregnancy*. <http://www.avert.org>
- Bennett, P. (1997) *Communicating About Risks to Public Health: Pointers to good practice*. London: DH.
- Calman, K.C., Royston, G.H.D. (1997) Risk language and dialects. *British Medical Journal*; **315**: 939–942.
- Cancer Research Campaign (2004) *Statistics: breast cancer*. <http://www.cancerresearchuk.org>
- Chief Medical Officer (2004) *Annual Report*. London: DH
- Edwards, A., Elwyn, G., Mulley, A. (2002) Explaining risks: turning numerical data into meaningful pictures. *British Medical Journal*; **324**: 827–830.
- Gigerenzer, G. (2002) *Reckoning With Risk*. London: Penguin.
- Health Protection Agency (2004) *Diagnoses and Rates of Selected STIs seen at GUM Clinics: 1999–2003*. London: HPA.
- Jain, B.P., McQuay, H., Moore, A. (1998) Number needed to treat and relative risk reduction. *Annals of Internal Medicine*; **128**: 72–73.
- Kitzinger, J. (1990) Audience understanding of AIDS media messages: a discussion of methods. *Sociology of Health and Illness*; **12**: 319–335.
- Levy, H.L., Mitchell, M.L. (1982) The current status of newborn screening. *Hospital Practice*; **17**: 89–97.
- Marteau, T.M. (1999) Communicating genetic information. *British Medical Bulletin*; **55**: 414–428.
- National Down's Syndrome Screening Programme for England (2004) *A Handbook for Staff*. London: UK National Screening Committee Programmes Directorate.
- Scriver, C.R. (1995) The hyperphenylalaninaemias. In: Scriver, C.R., Sly, W.S., Beaudet, A.L., Valle, D. (eds) *The Metabolic and Molecular Bases of Inherited Diseases*. New York: McGraw-Hill.
- Sickle Cell Society (2004) *Who gets SCDs?* <http://www.sicklecellsociety.org>
- Smith, I., Cook, B., Beasley, M. (1991) Review of neonatal screening programme for phenylketonuria. *British Medical Journal*; **303**: 333–335.
- UK Newborn Screening Programme Centre (2005) *Newborn Blood Spot Screening in the UK: Health professional handbook and Newborn Blood Spot Screening in the UK: Training resources*. London: UKNSPC.
- Wald, N., Kennard, A., Donnenfeld, A., Leck, I. (2000) Ultrasound scanning for congenital abnormalities. In: Wald, N., Leck, I. (eds) *Antenatal and Neonatal Screening* (2nd edn). Oxford: Oxford University Press.
- Walter, F.M., Britten, N. (2002) Patients' understanding of risk: a qualitative study of decision-making about the menopause and hormone replacement therapy in general practice. *Family Practice*; **19**: 6, 579–586.

Websites

- Antenatal Results and Choices (ARC): <http://www.arc-uk.org>
- DR Chris Cates' EBM Website: <http://www.nntonline.com>
- National Electronic Library for Health screening CPD website: <http://www.nelh.nhs.uk/screening/cpd/home.htm>
- Numbers needed to treat (Bandolier): <http://www.jr2.ox.ac.uk/bandolier/band59/NNT1.html>

Unit: Understanding and communicating risk

Certificate of completion

This certificate acknowledges that I have worked through the above unit from the Screening Choices programme at Core/Advanced* level, and I have achieved its learning outcomes.

I am able to:

- Acknowledge individual variation in perception of risk in both professionals and service users, give examples and understand the underlying factors
- Discuss the concept of framing and ways in which professional presentation of risk can influence women and their partners'/families' understanding
- Understand how epidemiology contributes to the understanding of risk in health and screening
- Explain absolute and relative risk and their relevance to the antenatal and newborn screening programmes
- Discuss different uses of the term 'risk' eg, chance, probability, uncertainty
- Understand the different approaches to communicating the same risk.

I attach evidence of my learning and confirm that this is a result of my own endeavours and fully acknowledges the work of others.

Signature

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Name

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Job title

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Date

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* Delete as appropriate